



Perinatal grief following a termination of pregnancy for fetal abnormality: the impact of coping strategies

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Bulleled statement:

What's already known about this topic:

- TFA can have long-lasting psychological consequences
- Little is known about the coping strategies used to deal with TFA

What this study adds:

- Despite using adaptive strategies, levels of grief are high
- Coping strategies predict perinatal grief in the context of TFA
- Acceptance and positive reframing lead to better adjustment

- Using Cognitive Behavioural Therapy or ACT may benefit women

For Peer Review

1 **ABSTRACT**

2 **Objective:** Pregnancy termination for fetal abnormality (TFA) can have significant
3 psychological repercussions, but little is known about the coping strategies involved in
4 dealing with TFA. This study examined the relationships between women’s coping strategies
5 and perinatal grief.

6 **Method:** 166 women completed a survey online. Coping and perinatal grief were measured
7 using the Brief COPE and Short Perinatal Grief scales. Data were analysed through multiple
8 regression analyses.

9 **Results:** Despite using mostly adaptive coping strategies, women’s levels of grief were high
10 and varied according to obstetric and termination variables. Grief was predicted by:
11 behavioural disengagement, venting, planning, religion, self-blame, being recently
12 bereaved, being childless at the time of TFA, not having had children/being pregnant since
13 TFA, and uncertainty about the decision to terminate the pregnancy. Acceptance and
14 positive reframing negatively predicted grief.

15 **Conclusion:** Identifying women vulnerable to poor psychological adjustment and promoting
16 coping strategies associated with lower levels of grief may be beneficial. This could be
17 addressed through information provision and interventions such as CBT or Acceptance and
18 Commitment Therapy.

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21 INTRODUCTION

22 Pregnancy termination for fetal abnormality (TFA) is a major life event that can have long-
23 term psychological consequences for women and their families. Although the prevalence of
24 TFA is low (e.g. 1% of all terminations in England and Wales in 2011¹), it is likely to increase
25 with the introduction of non-invasive prenatal testing techniques (e.g. cell-free DNA) and
26 the delay in child bearing age resulting in higher risks of gynaecological and obstetric
27 complications.² Women may experience a range of negative emotions post-TFA³⁻⁵ and,
28 although distress usually subsides over time, grief reactions can be observed years after the
29 termination.^{6,7}

30 The importance of coping strategies in psychological adaptation to adverse events is
31 evident in many health conditions where individuals facing similar events adjust
32 differently.^{8,9} Coping can be defined as “cognitive and behavioural efforts to manage specific
33 external and/or internal demands that are appraised as taxing or exceeding the resources of
34 the person.”^{10, p141} It involves a series of processes that occur when one faces a stressful
35 event, with some focusing on appraising the event (perception and evaluation of the event),
36 and others on coping *per se* (resources involved in dealing with the event). Within the field
37 of TFA, there is little understanding of the way women cope with this event, the complexity
38 of the strategies involved and the role these play in women’s psychological adaptation.

39 As a major life event, with potential complex and long-lasting consequences, it is
40 important for clinicians to understand women’s coping strategies when dealing with TFA to
41 promote optimum care to women and their families in both the immediate and longer-
42 term. In this study, we examined women’s coping strategies when dealing with TFA and
43 their levels of perinatal grief. In particular, we assessed whether coping strategies predict

44 levels of perinatal grief and identified the coping strategies most associated with positive
45 psychological adaptation.

46 **METHODS**

47 A cross-sectional survey was conducted with 166 members of a British support group, which
48 offers support to parents who are faced with a diagnosis of fetal abnormality. Participants
49 were recruited through the group e-mail network and forum and completed the survey
50 online between April 2011 and July 2012. All participants were female, over 18 years old,
51 and had undergone TFA. Participants completed two standardised scales, the Brief COPE¹¹
52 and the Short Perinatal Grief Scale (Short PGS).¹² The Brief COPE is a short version of the
53 COPE Inventory¹³ and assesses various coping strategies. It comprises 28 items measuring
54 14 different strategies (self-distraction, active coping, denial, substance use, use of
55 emotional support, use of instrumental support, humour, behavioural disengagement,
56 venting, positive reframing, planning, acceptance, religion and self-blame) and uses a 4-
57 point Likert scale (*I haven't been doing this at all* to *I've been doing this a lot*). Based on
58 Carver's guidelines,¹¹ the instructions' wording was tailored to the study. The subscale
59 'humour' was removed because it was deemed insensitive. The Brief Cope's validity and
60 reliability are well established with Cronbach's alpha values ranging from 0.50 to 0.90.¹¹
61 Participants were allocated a score between 2 and 8 on each subscale, 8 representing
62 highest usage of that particular coping strategy.

63 The Short PGS derives from the Perinatal Grief Scale.¹⁴ It comprises 33 items scored
64 on a 5-point Likert scale (*Strongly agree* to *Strongly disagree*). Items are grouped into three
65 11-item subscales (active grief, difficulty coping and despair) illustrating progressive
66 pathological levels of grief. Active grief represents 'uncomplicated grief' and covers items

67 such as crying for and missing the baby, whereas difficulty coping and despair characterise
68 'complicated grief.' Difficulty coping illustrates withdrawal and difficulties in dealing with
69 grief and daily functioning, while despair encompasses constructs such as guilt, emptiness
70 and worthlessness. The three subscales are aggregated into a general grief scale. Higher
71 scores reflect higher levels of grief. Scores range from 11 to 55 for the subscales and from
72 33 to 165 for the general grief scale. Cronbach's alpha values for the Short PGS have varied
73 between 0.86 and 0.92.¹²

74 Questions related to the terminated pregnancy were also included, e.g. gestational
75 age, termination method, fetal abnormality prognosis (lethal/non-lethal), whether women
76 had living children at the time of TFA, whether this was their first pregnancy, feeling about
77 the decision to terminate (would/would not make the same decision again), time elapsed
78 since TFA. Demographic data (e.g. age, education level, ethnicity) were also collected.

79 The online survey was hosted by a secure website (SurveyMonkey). Participants
80 could leave and re-enter the survey, enabling them to complete it at their own pace. The
81 questionnaire was piloted on three participants; no changes were made as a result. Ethical
82 approval was obtained from a University Ethics Committee in South-East England.
83 Participants were given information about the study and consent was obtained for all of
84 them. Participants were given the telephone number of the group helpline and had access
85 to the group's volunteer network. The first author's membership of the group's volunteer
86 network raised possible ethical issues of duality of roles and confidentiality. Thus, the first
87 author's name was removed from the list of volunteers available to participants.

88 Data were analysed using SPSS (version 21, SPSS Inc, Chicago). To examine the
89 relationship between women's coping strategies and their perinatal grief, the 13 Brief COPE
90 subscales were used as predictors and the four Short PGS scales as outcomes. Grief levels

91 were compared across obstetric and demographic groups using a one-way analysis of
92 variance (ANOVA) test, followed by Bonferroni *post hoc* test (equal variances) and *t*-tests.
93 Variables exhibiting significant correlations with the grief variables were included in the
94 regression analyses. Multiple hierarchical regressions were run for each of the grief scales
95 individually. Coping strategies were entered first and TFA variables second. For all tests, *p*-
96 values < 0.05 were considered statistically significant.

97 **RESULTS**

98 In total 215 participants took part in the study. Of those 38 did not complete the survey in
99 full, and a further 11 were identified as duplicates. Thus, the total number of completed
100 questionnaires is 166. Table 1 shows the demographic and obstetric profile of the
101 participants. Participants were aged between 22 and 46 years old (mean: 34.5, SD: 4.9), the
102 majority (70.5%, *n* = 117) were University-level educated. All but one participant were
103 married or in a relationship, and almost all 97.0% (*n* = 130¹) were White. Pregnancies were
104 terminated between 12 and 35 weeks of gestation (mean: 18.5, SD: 4.9). For approximately
105 half the participants (53.0%, *n* = 88), termination had occurred less than 6 months before
106 interview. Most terminations were medical (77.7%, *n* = 129). For 70 participants (42.2%),
107 this represented their first pregnancy.

108

109 *Insert Table 1 here*

110

¹ Data on ethnicity are based on 134 responses.

Use of coping strategies and levels of perinatal grief are shown in Table 2. Both scales displayed satisfactory levels of internal reliability with Cronbach's alpha values for the Short PGS of 0.83 for active grief and despair, 0.86 for difficulty coping and 0.93 for the general grief subscale. For the Brief COPE, Cronbach's alpha values ranged from 0.56 for behavioural disengagement to 0.96 for substance use. The subscale denial did not satisfy the minimum requirement of 0.5¹⁵ with a value of 0.48, and thus was excluded from further analysis. Overall, women used mainly adaptive coping strategies when dealing with TFA including acceptance, emotional support, active coping, planning and instrumental support. The scores for these variables were above the midpoint value of 5. The mean score for self-distraction, often considered a maladaptive strategy, was also above the midpoint. By contrast, behavioural disengagement or substance use registered the lowest usage (2.8 and 2.9 respectively). These scores are comparable to other studies using the Brief COPE.¹⁶

Despite using mostly adaptive coping strategies, levels of grief were high. Similarly to other studies using the Short PGS,¹⁷ the mean scores for the three subscales decreased progressively indicating incremental levels of pathological grief, so that the highest scores were recorded for active grief and the lowest for despair. Mean scores for active grief (41.5) and general grief (104.1) were above the midpoint (33 and 99 respectively), whereas scores for difficulty coping (33.1) and despair (29.5) were on or below the midpoint.

Insert Table 2 here

Levels of grief differed according to variables related to the terminated pregnancy (Table 3). Higher levels of grief were observed among women who were childless at the time of TFA (all grief variables), for whom it was the first pregnancy (all grief variables), who

were not pregnant/had not had children since TFA (all grief variables), who would not/were unsure they would make the same decision to terminate again (difficulty coping, despair and general grief) and who were more recently bereaved, i.e. in the previous 6 months (active grief and general grief). Differences between age groups were noticeable, with women under 35 displaying higher levels of active grief. No significant differences were observed across groups for termination method, gestational age, abnormality prognosis, or education level.

Insert Table 3 here

Scores on the grief subscales were highly inter-correlated (r ranging from 0.70 to 0.93). Adaptive coping strategies were positively correlated with each other (e.g. positive re-framing and acceptance $r = 0.43, p < 0.01$) and negatively correlated with grief scales (e.g. acceptance and general grief $r = -0.47, p < 0.01$). Maladaptive strategies were also correlated with each other (e.g. behavioural disengagement and self-blame, $r = 0.22, p < 0.01$) and positively correlated with grief (e.g. behavioural disengagement and general grief $r = 0.44, p < 0.01$). Correlations between demographic and grief variables were not significant, except for age, which exhibited a weak negative correlation with active grief ($r = -0.19, p < 0.05$) and general grief ($r = -0.17, p < 0.05$). Point-biserial correlations between dichotomous TFA variables and grief variables were significant for: having living children at the time of TFA, being pregnant/having had children since TFA, and whether they would/would not make the same decision again. Statistically significant correlations are shown in tables 4 and 5.

159 *Insert Tables 4 and 5 here*

160

161 Variables showing a significant correlation with grief variables were used as
162 predictors in the multiple regression analyses. Individual models were run for each grief
163 variable based on its own set of predictors.² The resulting hierarchical regression models are
164 shown in Table 6. Active grief was positively predicted by self-blame, religion, planning and
165 behavioural disengagement, and negatively predicted by acceptance and time elapsed since
166 termination (highest scores among those who underwent TFA 6 months prior). Difficulty
167 coping was positively predicted by self-blame, behavioural disengagement, venting and
168 feeling about the decision (highest scores among those who would not/were unsure they
169 would make the same decision again); difficulty coping was negatively predicted by
170 acceptance, positive reframing, time elapsed since termination, having living children at the
171 time of TFA (highest scores among those who were childless) and by being pregnant/having
172 had children since TFA (highest scores among those who were not pregnant/did not have
173 children). Despair was positively predicted by self-blame, behavioural disengagement, and
174 feeling about the decision, and negatively predicted by acceptance, having living children at
175 the time of TFA and being pregnant/having had children since TFA. General grief was
176 positively predicted by self-blame, behavioural disengagement, venting, planning, religion,
177 feeling about the decision, and negatively predicted by acceptance, positive reframing, time

² Although the 'first pregnancy' variable was significantly correlated with all grief subscales, it was excluded from the analysis because it was highly correlated with the 'having living children at the time of TFA' variable ($r = 0.81$, $p < 0.001$) and found to be statistically less useful. Furthermore, the variable 'having living children at the time of TFA' reflects women's obstetric history more accurately as number of pregnancies does not necessarily equate to number of living children. Similarly, although 'age' was significantly negatively correlated with active grief and general grief, its predictive value was weak and thus, was removed from the analysis.

since termination, having living children at the time of TFA and being pregnant/having had children since TFA.

The total amount of variance explained by the models was high: 50.5% for active grief, 59.7% for difficulty coping, 53.3% for despair and 64.6% for general grief. TFA variables accounted for 8.6% (difficulty coping, despair), 10.8% (general grief) and 13.1% (active grief) of the variance.

Insert Table 6 here

DISCUSSION

This study indicates that a relationship exists between the coping strategies used by women when dealing with TFA and their levels of grief. When controlling for obstetric and termination variables, women who reported using strategies such as acceptance and positive reframing fared better psychologically than those who used more maladaptive strategies such as self-blame, or behavioural disengagement. These findings support the hypothesis that the use of maladaptive strategies may lead to poorer psychological outcome.

However, it is also remarkable that despite the use of adaptive coping strategies, women's levels of grief were higher than in other studies using the Short PGS and that a significant proportion of participants displayed pathological grief levels that may meet criteria for complicated grief. In a review of studies using the PGS, Toedter and colleagues suggested that scores above 34 for active grief, 30 for difficulty coping, 27 for despair and 91 for general grief indicated complicated grief.¹⁸ In our study, 79.5% (n = 132) of the women scored above 34 for active grief, 59.6% (n = 99) above 30 for difficulty coping, 56.6% (n = 94)

above 27 for despair, and 69.9 (n= 116) above 91 for general grief. Similarly, in a study of emotional responses to TFA, mean scores for the general grief scale ranged between 76 and 85, well below the levels observed in our study (104.1).¹⁹

This finding is clinically relevant given that complicated grief is to be included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). This inclusion has generated debate with some arguing that it is necessary to ensure that those suffering receive help,²⁰ while others raise issues of false-positive diagnosis and medicalisation of normal human emotions.²¹ The high levels of grief in the presence of adaptive coping strategies also leads us to question the validity of classifying coping strategies into distinct categories such as adaptive/maladaptive. In the past 20 years, researchers have promoted a more granular and multidimensional approach to coping, which they believe reflects more accurately the complexity of coping processes.¹¹ In this study, when traditionally labelled maladaptive strategies were used (e.g. behavioural disengagement) they might have served an adaptive function. Although possibly maladaptive in the long-term, these strategies may have contributed to protecting women from emotional distress in the short-term.²² Similarly, the use of self-blame may reflect characteristics unique to TFA. Indeed, it may be unsurprising that some women experience a degree of self-blame given that they, along with their partners, bear the responsibility for terminating their pregnancy. Thus, in this context self-blame may reflect a feeling inherent to the nature of the loss rather than a coping strategy *per se*.

The levels of grief in this study varied based on obstetric and termination variables, with higher levels of grief recorded among women more recently bereaved, those who were childless at the time of TFA, who were not pregnant/had not had children since TFA and

who would not/were unsure they would make the same decision again. Similar findings have been reported in the TFA literature.²³⁻²⁵

The high levels of grief may be explained by a number of factors. The first may be the recency of the termination. Over half the participants had experienced their loss 6 months or less prior to participating in the study and evidence has shown that emotional distress peaks in the first year following TFA.²⁶ Our study seems to support this as levels of grief were lower as time elapsed. The use of a support group may also be related to levels of grief as all participants were, to some degree, active on the support group e-mail network or forum. It is plausible that women who experience high levels of emotional distress may be more likely to use an online support group, although there is currently no evidence to support this hypothesis in the context of TFA. Another, and not inconsistent explanation, is that the way people use an online support group may influence their emotional well-being.

The health benefits of self-disclosure, a central component of using online support groups, have been well documented.^{27,28} However, direct evidence of the psychological benefits of engagement with online-support groups is inconclusive.²⁹ Some studies suggest that using an online support group may provide a forum for self-expression, social support and a sense of empowerment, which collectively act as a buffer against distress.^{30,31} Conversely a study of peer-to-peer interactions in an online support group for women with breast cancer, indicates that members who concentrate on their own story tend to experience more psychological distress than those open to the story of other members.³² Although the causal direction of this relationship is difficult to determine, this may support our study's finding linking venting to poorer psychological adjustment. Other studies have also underlined (among the many benefits of online communities) the potential for the use of online support groups to lead to rumination.³³ Thus, the nature of interactions and the

depth of involvement in the support group environment may influence women's psychological adjustment. In line with this hypothesis, research has shown that women who do not seek professional help following TFA and do not engage in bereavement ritual adjust better than those who do.⁷ Further research would be needed to ascertain the impact of online support groups on psychological adjustment in the context of TFA, and the direction of any relationships.

The study also indicates that there is some value in identifying women vulnerable to poor psychological adaptation following TFA, and suggests a number of risk factors, mostly outside women's control (time since termination, having children at the time/since TFA, feeling about the decision). The study also underlines a number of protective factors which may enhance women's psychological adjustment, including coping strategies such as acceptance and positive reframing. Therefore, it may be beneficial to promote such strategies through information provision or talking therapies. For example, interventions based on Cognitive Behavioural Therapy that aim to alter cognitions may be appropriate. Similarly, Acceptance and Commitment Therapy (ACT), which blends 'acceptance and mindfulness strategies with commitment and behaviour change strategies'³⁴ may be helpful. ACT consists of embracing experiences, acknowledging the feelings and cognitions that accompany these and devising a course of action in accordance with the individual's values.³⁵ It may also be beneficial to minimise the use of less helpful coping strategies such as behavioural disengagement, and address issues of self-blame. Finally, it may be helpful to highlight the range of emotions women may experience post-termination, including relational tensions,³⁶ feeling of inadequacy³⁷ but also a sense of renewed strength and personal growth.³⁸

In light of these considerations, it is important that the care provided to women is sensitive and adapted to individual needs. A core component of providing appropriate care may lie in understanding the nature of the loss. Bereavement following TFA has been compared to bereavement after stillbirth.³⁹ However, although the unexpected nature of stillbirth may impact the grieving process, elements specific to TFA (e.g. possible doubt or guilt over the decision, concern about being judged by others) may also complicate the grieving process. The way women adjust to TFA is important to their quality of life as a whole. It may also significantly impact the way they manage subsequent pregnancies, as women who have experienced pregnancy loss may display higher levels of anxiety and depression during subsequent pregnancy than those who have not.⁴⁰

To our knowledge, this study is among the first to examine the direct relationship between coping strategies and perinatal grief within the context of TFA. Thus, it provides valuable insights into the way coping strategies impact psychological adjustment to TFA. The amount of variance explained by the regression models was high (50.5 to 64.6%), which alongside the statistically significant reports of analysis of variance (ANOVA) in the models, indicates that coping strategies are strong predictors of grief. Finally, in addition to highlighting important intervention implications, this study identifies several new research directions.

Longitudinal research is needed to establish directional causality between women's coping strategies and their grief levels, and to identify the role of moderating and mediating variables. A longitudinal design would also facilitate cross-validation of self-reports to address possible *post hoc* rationalisation or social desirability bias in women's responses. In this study some participants may have under-reported their use of less adaptive strategies (e.g. substance use) or grief levels. It would also be beneficial to examine the role of online

295 support group participation on psychological adaptation to TFA, particularly, the importance
296 of different levels and styles of user involvement e.g. posters vs. lurkers. Finally, researchers
297 need to address the coping strategies of women who do not participate in support groups
298 either through choice or inability to access a group. Our participant profile was
299 predominantly White, well-educated and in a relationship. Many TFA studies report similar
300 sampling issues.^{26,41} Although this profile is a valid reflection of the support group's
301 membership we sampled from, it is not fully representative of women experiencing TFA.
302 Evidence from these new directions will provide a more comprehensive account of what
303 coping with TFA involves.

References

- 1 Department of Health. Abortions statistics, England & Wales: 2011.
<http://mediacentre.dh.gov.uk/2012/05/29/abortion-statistics-england-wales-2011>
[accessed 20 July 2012].
- 2 Royal College of Obstetricians and Gynaecologists. RCOG statement on later maternal age. 2009 <http://www.rcog.org.uk/what-we-do/campaigning-and-opinions/statement/rcog-statement-later-maternal-age> [accessed 12 April 2012].
- 3 Korenromp MJ, Christiaens GC, Van den Bout J, *et al.* A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenat Diagn.* 2007; 27(8):709-16.
- 4 Davies V, Gledhill J, McFadyen A, Whitlow B, Economides D. Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study. *Ultrasound Obstet Gynecol.* 2005; 25(4):389-92.
- 5 Statham H, Solomou W, Green JM. When a baby has an abnormality: A study of parents' experiences. Cambridge, UK: University of Cambridge, Centre for Family Research; 2001. 274 p. Report to the NHS Executive (Mother and Child Health Initiative) of grant no. MCH 4-12. Cambridge.
- 6 Korenromp MJ, Christiaens GC, Van den Bout J, *et al.* Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenat Diagn.* 2005; 25(3):253-60.
- 7 Green JM, Statham HE. Psychosocial aspects of prenatal diagnosis: the challenges for doctors and patients. In *Psychological challenges in obstetrics and gynaecology: the*

- clinical management, Cockburn J, Pawson M (eds). London: Springer-Verlag Ltd, 2007; 107-20.
- 8 Schnider K, Elhai J, Gray M. (2007). Coping style predict posttraumatic stress and complicated grief symptoms severity among college students reporting a traumatic loss. *J Couns Psychol.* 2007; 54 (3):344-50.
 - 9 Cartwright T, Endean N, Porter A. (2009). Illness perceptions, coping and quality of life in patients with alopecia. *Br J Dermatol.* 2009; 160(5):1034-9.
 - 10 Lazarus RS, Folkman S. *Stress, Appraisal and Coping.* New York: Springer Publishing Company, 1984.
 - 11 Carver CS. You want to measure coping but your protocol's too long: consider the Brief COPE. *Int J Behav Med.* 1997; 4(1):92-100.
 - 12 Potvin L, Lasker J, Toedter L. Measuring grief: a short version of the Perinatal Grief Scale. *J Psych Behav Assessment.* 1989; 11(1):29-45.
 - 13 Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol.* 1989; 56:267-83.
 - 14 Toedter LJ, Lasker JN, Alhadeff JM. The Perinatal Grief Scale: Development and initial validation. *Am J Orthopsychiatry.* 1988; 58(3):435-49.
 - 15 Nunally, JC. *Psychometric theory.* New York: McGraw-Hill, 1978.
 - 16 Perczek R, Carver CS, Price AA, Pozo-Kaderman C. Coping, mood and aspects of personality in Spanish translation and evidence of convergence with English version. *J Pers Assess.* 2000; 74(1):63-87.
 - 17 Lasker JN, Toedter LJ. Acute versus chronic grief: the case of pregnancy loss. *Am J Orthopsychiatry.* 1991; 61(4):510-22.

- 18 Toedter LJ, Lasker JN, Janssen HJEM. International comparison of studies using the Perinatal Grief Scale: a decade of research on pregnancy loss. *Death Stud.* 2001; 25:205-28.
- 19 Hunfeld JAM, Wladimiroff JW, Passchier J. Pregnancy termination, perceived control and perinatal grief. *Psychological Reports* 1994; 74:217-18.
- 20 Shear MK, Simon N, Wall M *et al.* Complicated grief and related bereavement issues for DSM-5. *Depress Anxiety.* 2011; 28(2):103-17.
- 21 Wakefield JC. Should prolonged grief be reclassified as a mental disorder in DSM-5?: reconsidering the empirical and conceptual arguments for complicated grief disorder. *J Nerv Ment Dis.* 2012; 200(6):499-511.
- 22 Reference anonymised for review process. *Qual Health Research* 2013 (in press)
- 23 Statham H. Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences. *Fetal Maternal Medical Review* 2002; 13:213- 47.
- 24 Fisher J, Statham H. Parental reaction to prenatal diagnosis and subsequent bereavement. In *Fetal Medicine: basic science and clinical practice*, Rodeck CH, Whittle MJ (eds). London: Churchill Livingstone Elsevier, 2009; 234-42.
- 25 Korenromp MJ, Iedema-Kuiper HR, van Spijker HG *et al.* (1992). Termination of pregnancy on genetic grounds: coping with grieving. *J Psychosom Obstet Gynaecol.* 1992; 13: 93-105.
- 26 Korenromp MJ, Page-Christiaens GCML, van der Bout J *et al.* Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8 and 16 months. *Am J Obstet Gynecol* 2009; 201:160.e1-7.

- 27 Pennebaker JW. Confession, inhibition and disease. In *Advances in Experimental Social Psychology*, Berkowitz L (ed). New York: Academic Press Vol.22, 1989; 211-44.
- 28 Stanton AL, Danoff-Burg S, Sworowski, LA *et al*. Randomized, controlled trial of written emotional expression and benefit finding in breast cancer patients. *J Clin Oncol*. 2002; 20: 4160–8.
- 29 Eysenbach G, Powell J, Englesakis M *et al*. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ* 2004; 328(7449):1166.
- 30 Barak A, Boniel-Nissom M, Suler J. Fostering empowerment in on-line support group. *Computer in Human Behavior* 2008; 24:1867-83.
- 31 Wright KB, Bell SB. Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated communication theory. *J Health Psychol* 2003; 8(1): 39–54.
- 32 Shaw BR, Han JY, Hawkins RB *et al*. Communicating about self and others within an Online Support Group for Women with Breast Cancer and Subsequent Outcomes. *J Health Psychol* 2008; 13(7):930–9.
- 33 Malik SH, Coulson NS. Computer-mediated infertility support groups: An exploratory study of online experiences. *Patient Educ Couns* 2008; 73(1): 105-13.
- 34 British Association for Behavioural and Cognitive Psychotherapies. Acceptance and Commitment Therapy (ACT). <http://www.babcp.com/Membership/SIG/ACT.aspx> [accessed on 14 February 2013].
- 35 Hayes SC. Acceptance and Commitment Therapy, Relational Frame Theory, and the Third Wave of Behavioral and Cognitive Therapies. *Behav Ther*. 2004; 35:639-65.

- 36 Rillstone P, Hutchinson, SA. Managing the reemergence of anguish: Pregnancy after a loss due to anomalies. *J Obstet Gynecol Neonatal Nurs*. 2001; 30(3):291-8.
- 37 Bryar SH. One day you're pregnant and one day you're not: pregnancy interruption for fetal anomalies. *J Obstet Gynecol Neonatal Nurs*. 1997; 26(5): 559-66.
- 38 Ferreira da Costa LdeL, Hardy E, Duarte Osis MJ, Faúndes A. Termination of pregnancy for fetal abnormality incompatible with life: women's experiences in Brazil. *Reprod Health Matters* 2005; 13(26): 139-46.
- 39 Salvesen KA, Oyen L, Schmidt N, *et al*. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. *Ultrasound Obstet Gynecol*. 1997; 9(2):80-5.
- 40 Blackmore RE, Côté-Arsenault D, Tang W *et al*. Previous prenatal loss as a predictor of perinatal depression and anxiety. *Br J Psychiatry*. 2011; 198:373–8.
- 41 McCoyd JL. Pregnancy interrupted: loss of a desired pregnancy after diagnosis of fetal anomaly. *J Psychosom Obstet Gynaecol*. 2007; 28(1):37-48.

Table 1 – Participants' demographic and obstetric profile. Data are presented as number and percentage or as mean, SD, and range

	N	%	Mean	SD	Range
DEMOGRAPHIC PROFILE					
Age	166		34.5	4.9	22-46
Education					
Secondary	49	29.5			
Graduate	67	40.4			
Postgraduate	50	30.1			
Ethnicity - White	130	97.0			
OBSTETRIC PROFILE					
Time since termination					
Up to 6 months	88	53.0			
7-12 months	35	21.1			
12-24 months	28	16.9			
24 months+	15	9.0			
Gestational age at TFA	166		18.5	4.9	12-35
Method of termination					
Medical	129	77.7			
Surgical	36	21.7			
Abnormality prognosis – Lethal	68	41.0			
Children at time of TFA - Yes	77	46.3			
First pregnancy – Yes	70	42.2			
Would make the same decision again - Yes	122	73.5			
Children since TFA - Yes/pregnant	49	29.6			

Table 2 – Mean scores and standard deviation for the Brief COPE and Short PGS subscales

Brief COPE			Brief COPE		
	Mean	SD		Mean	SD
Self-distraction	5.22	1.71	Venting	4.77	1.75
Active coping	5.35	1.69	Positive reframing	4.34	1.86
Denial	3.04	1.20	Planning	5.28	1.78
Substance use	2.88	1.52	Acceptance	5.96	1.56
Emotional support	5.93	1.70	Religion	3.14	1.70
Instrumental support	5.21	1.68	Self-blame	4.81	1.90
Behavioural disengagement	2.82	1.18			
Short PGS			Short PGS		
Active grief (11-55)	41.53	7.08	Despair (11-55)	29.49	7.99
Difficulty coping (11-55)	33.11	8.62	General grief (33-165)	104.14	21.58

Values above the mid-point are highlighted in bold – Brief COPE: > 5, Active grief, Difficulty coping and Despair: > 33 and General grief: >99

Table 3 – Significant group differences on Short PGS subscale by obstetric and demographic variables

	Yes	No	t-value	
Children at time of TFA	N= 77 (46.3%)	N= 89 (53.6 %)		
Active grief	40.14 (SD: 7.44)	42.73 (SD: 6.56)	2.38	p = 0.018
Difficulty coping	31.22 (SD: 8.71)	34.75 (SD: 8.24)	2.68	p = 0.008
Despair	27.36 (SD: 7.49)	31.34 (SD: 7.99)	3.29	p = 0.001
General grief	98.72 (SD: 21.58)	108.82 (SD: 20.58)	3.08	p = 0.002
First Pregnancy	N= 70 (42.2%)	N = 96 (57.8%)		
Active grief	43.33 (SD: 6.11)	40.22 (7.47)	2.86	p = 0.005
Difficulty coping	34.86 (SD: 7.93)	31.84 (8.92)	2.25	p = 0.026
Despair	31.50 (SD: 7.85)	28.03 (SD: 7.81)	2.82	p = 0.005
General grief	109.69 (SD: 19.69)	100.09 (SD: 22.10)	2.89	p = 0.004
Children post-TFA	N = 49	N = 117		
Active grief	38.55 (SD: 7.60)	42.78 (SD: 6.48)	3.64	p = 0.000
Difficulty coping	29.88 (SD: 8.57)	34.47 (SD: 8.31)	3.22	p = 0.002
Despair	27.45 (SD: 7.93)	30.35 (SD: 7.89)	2.16	p = 0.032
General grief	95.88 (SD: 22.14)	107.60 (20.47)	3.29	p = 0.001
Same decision again	N = 122 (73.5)	N = 44 (26.5)*		
Active grief	41.10 (SD: 7.02)	42.73 (SD: 7.18)	-1.31	p = 0.191
Difficulty coping	32.05 (8.39)	36.07 (SD: 8.67)	-2.70	p = 0.008
Despair	27.98 (7.58)	33.68 (7.66)	-4.26	p = 0.000
General grief	101.13 (20.73)	112.48 (21.95)	-3.06	p = 0.003
Age	Up to 35 years old	35 +		
	N= 88 (53%)	78 (47%)		
Active grief	42.58 (SD: 6.52)	40.35 (SD: 7.53)	2.05	p = 0.042
Difficulty coping	34.06 (SD: 8.25)	32.05 (SD: 8.96)	1.50	p = 0.135
Despair	30.22 (SD: 8.42)	28.68 (SD: 7.44)	1.24	p = 0.22
General grief	106.85 (SD:20.89)	101.08 (SD: 22.07)	1.73	p = 0.09
Time since termination	Up to 6 months	6-12 months	12-24 months	24+
Active grief	43.80 (6.13)	40.29 (6.58)	38.64 (6.61)**	36.53 (9.36)**
Difficulty coping ⁺	34.72 (8.56)	33.00 (8.25)	30.14 (8.24)	29.53 (8.78)
Despair	30.15 (7.74)	29.71 (9.07)	27.61 (7.20)	28.67 (8.33)
General grief	108.66 (20.41)	103.00 (22.09)	96.39 (19.76)*	94.73 (24.83)

Comparison between each group was by t-tests for all variables except for the 'Time since termination' variable, for which a one-way analysis of variance (ANOVA) with *post-hoc* Bonferroni test was used. Groups were compared against the most recently bereaved group (up to 6 months), * p < 0.05, ** p < 0.01, *** p < 0.001

⁺ There was a main effect of 'time since termination' on 'difficulty coping'; F (3-162) = 3.10, p < 0.028, but Bonferroni tests did not reveal any significant pair-wise differences

Table 4 – Overview of statistically significant correlations between Brief COPE and Short PGS scales

	Self- distraction	Active Coping	Emotional Support	Instrumental Support	Behavioural Disengagement	Venting	Positive Reframing	Planning	Acceptance	Religion	Self- blame	Active Grief	Difficulty Coping	Despair
Self-distraction														
Active Coping	.169*													
Substance Use														
Emotional Support		.397**												
Instrumental Support		.401**	.610**											
Behavioural Disengagement														
Venting		.324**	.438**	.391**	.155*									
Positive Reframing		.352**	.276**	.228**										
Planning	.172*	.474**	.274**	.361**	.156*	.305**								
Acceptance	.235**	.386**	.358**	.181*	-.201**		.425**							
Religion							.180*							
Self-blame					.217**			.210**	-.186*	.222**				
Active Grief					.344**	.246**	-.211**	.267**	-.383**	.199*	.404**			
Difficulty Coping					.466**	.272**	-.330**	.242**	-.438**		.477**	.755**		
Despair			-.187*		.372**		-.244**	.182*	-.446**		.540**	.704**	.769**	
General Grief					.437**	.238**	-.291**	.252**	-.466**	.170*	.523**	.890**	.931**	.908**

*. Correlation is significant at the 0.05 level; **. Correlation is significant at the 0.01 level

Table 5 – Overview of statistically significant correlations between Short PGS scales and obstetric and demographic variables

	Active Grief	Difficulty Coping	Despair	General grief
Age	-.194 [*]			-.171 [*]
First pregnancy [†]	-.218 ^{**}	-.173 [*]	-.215 ^{**}	-.220 ^{**}
Children at time of TFA [†]	-.183 [*]	-.205 ^{**}	-.249 ^{**}	-.234 ^{**}
Children since TFA [†]	-.273 ^{**}	-.244 ^{**}	-.166 [*]	-.248 ^{**}
Feeling about decision [†]	.102	.206 ^{**}	.316 ^{**}	.233 ^{**}

*. Correlation is significant at the 0.05 level; **. Correlation is significant at the 0.01 level

† Point-biserial correlations

Table 6 – Results of multiple regression analysis for active grief, difficulty coping, despair and general grief scale.

Variable	Active grief	Difficulty coping	Despair	General grief
Step 1 - predictors	β	β	β	β
Behavioural disengagement	0.13*	0.24***	0.17**	0.20***
Venting	0.09	0.16**	n/a	0.12*
Planning	0.13*	0.10	0.09	0.12*
Religion	0.17**	n/a	n/a	0.11*
Self-blame	0.27***	0.30***	0.37***	0.33***
Positive reframing	-0.11	-0.18**	-0.06	-0.14**
Acceptance	-0.28***	-0.25***	-0.29***	-0.30***
Emotional support	n/a	n/a	-0.02	n/a
F model	15.33***	30.50***	23.73***	28.91***
R ₂ on step 1	0.38	0.52	0.45	0.54
Step 2: predictors				
Time since TFA	-0.33***	-0.17**	n/a	-0.22***
Children at TFA	-0.11	-0.12*	-0.18***	-0.15**
Children since TFA	-0.07	-0.14*	-0.20***	-0.13*
Feeling about TFA	n/a	0.15**	0.18**	0.16**
F model	17.86***	25.41***	21.92***	28.36***
R ₂ on step 2	0.51	0.60	0.53	0.65
^a Change in R ₂	0.13***	0.09***	0.09***	0.11***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$;^a difference in R₂ on steps 1 and 2, and the significance of F-change.